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# Congress of the United States

## House of Representatives

### COMMITTEE ON WAYS AND MEANS

WASHINGTON, DC 20515

#### SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Mr. Daniel Bertoni  
Director, Education, Workforce, and Income Security  
U.S. Government Accountability Office  
441 G Street, N.W.  
Washington, D.C. 20548

Dear Mr. Bertoni:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated your expertise as we seek to understand trends in the number of children receiving SSI due to mental impairments, the role of medication in disability determinations, and the impact of the failure to complete continuing disability reviews on program enrollment.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business Tuesday, November 15, 2011:

1. According to Social Security Administration data, last month the average SSI benefit overall was \$499, while the average SSI benefit for disabled adults was \$517, and the average SSI benefit for disabled children was \$597.

Why do children on SSI tend to receive larger disability benefits than other SSI recipients?

Are there any requirements that a child's SSI benefits, or any SSI disability payments for that matter, must be used to help the individual overcome their disability? If they do succeed in overcoming their disability, what happens to the benefit payments?

2. In our previous hearing on work incentives we found that only 3 percent of SSI adults leave the rolls due to work, while most leave through death, making it sound like SSI is a lifetime commitment.

Is this also a concern for children? What do we know about their durations as children and then as adults?

For example, what is the most common reason children on SSI lose eligibility? Medical improvement? Turning 18? Increased earnings by their parents? Their own earnings? Other reasons, such as the child dies as a result of their disabling condition or other causes?

The Committee relies on electronic submissions for printing of the official record. Therefore, please send an electronic submission in Word format to [timothy.ford@mail.house.gov](mailto:timothy.ford@mail.house.gov). If you have any questions concerning this matter, please feel free to contact Matt Weidinger or Anne DeCesaro of my staff at (202) 225-1025.

Again, many thanks. We will continue to be in touch with you if we have questions about your preliminary findings.

Sincerely,



Geoff Davis

- 1. According to Social Security Administration data, last month the average SSI benefit overall was \$499, while the average SSI benefit for disabled adults was \$517, and the average SSI benefits for disabled children was \$597.**

**Why do children on SSI tend to receive larger disability benefits than other SSI recipients?**

While we have not conducted the work necessary to answer this question, SSA attributes the relatively high average payment to children (compared with payments made to blind and disabled adults) in part to a limited amount of countable income. The federal SSI payment is based on the individual's countable income,<sup>1</sup> which for a child, may include the parent or guardian's income. SSA's process of determining how much of this income they will count towards the child's income is called "deeming." SSA will make deductions from deemed income for parents and for other children living in the home. After SSA subtracts these deductions, the agency determines whether the child meets the SSI income and resource requirements and calculates the recipient's monthly benefit payment.

**Are there any requirements that a child's SSI benefits, or any SSI disability payments for that matter, must be used to help the individual overcome their disability? If they do succeed in overcoming their disability, what happens to the benefit payments?**

Typically, a disabled child's SSI benefit is paid on behalf of the child to a "representative payee," such as a parent or guardian. The representative payee is responsible for using SSI payments only for the child's use and benefit in a manner and for the purposes he or she determines, consistent with SSA guidelines, to be in the child's best interests.<sup>2</sup> The representative payee of a child also has a responsibility to ensure that the child is receiving treatment to the extent considered medically necessary and available for the condition that was the basis for providing benefits.<sup>3</sup> "Treatment that is medically necessary" is treatment that is expected to improve or restore the child's functioning and that was prescribed by a treating source.<sup>4</sup> SSA is generally required by law to determine the extent to which certain child recipients have medically improved and are still eligible to receive benefits. At the time of this disability review, the child's representative payee generally must present evidence that the child is and

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<sup>1</sup>Some states supplement the federal SSI benefit with additional payments, making the total SSI benefit levels higher in those states. State supplemental payment amounts may vary based upon an individual's income.

<sup>2</sup>20 C.F.R. § 416.635(a).

<sup>3</sup>20 C.F.R. § 416.635(g).

<sup>4</sup>20 C.F.R. § 416.994a(i)(1).

has been receiving medically necessary and available treatment for his or her impairment. If the child is found to have medically improved and no longer meets SSI eligibility requirements, the recipient should no longer continue to receive benefit payments.<sup>5</sup>

- 2. In our previous hearing on work incentives we found that only 3 percent of SSI adults leave the rolls due to work, while most leave through death, making it sound like SSI is a lifetime commitment.**

**Is this also a concern for children? What do we know about their durations as children and then as adults?**

We have not conducted the work necessary to answer this question. However, SSA data suggest that between 1974 and 2010, 918,825 adult SSI recipients first became eligible for benefits before age 18.

**For example, what is the most common reason children on SSI lose eligibility? Medical Improvement? Turning 18? Increased earnings by their parents? Their own earnings? Other reasons, such as the child dies as a result of their disabling condition or other causes?**

SSA data indicate that between 2006 and 2010 the most common reason SSA terminated SSI benefits for both adult and child recipients was due to “excess income.” Of those recipients under age 18 terminated in 2010, about 51 percent were terminated because of excess income. Other reasons for benefit cessation include excess resources, death, or because they are no longer disabled (see table 1).

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<sup>5</sup>42 U.S.C. § 1382c(a)(4).

**Table 1: Recipients terminated, by age and reasons for termination, 2006-2010**

Year	Total	Excess Income	Death	Whereabouts Unknown	Excess Resources	In public institution	Failed to furnish report	Outside United States	No longer disabled	Other
<b>All ages</b>										
2006	735,148	339,110	244,013	10,333	25,947	29,797	9,106	13,369	46,561	16,912
2007	690,504	318,291	242,375	9,615	22,439	30,066	5,911	12,284	32,284	17,239
2008	699,627	324,285	244,412	9,496	24,547	29,613	6,860	13,444	30,671	16,299
2009	732,484	354,770	242,680	10,213	24,147	29,796	8,199	11,340	32,408	18,931
2010	815,946	437,922	241,148	11,397	29,184	27,408	10,163	10,527	34,675	13,522
<b>Under age 18</b>										
2006	65,132	26,241	5,236	2,654	5,257	1,360	3,188	547	17,536	3,113
2007	55,147	25,529	5,488	2,610	4,855	1,420	2,055	522	9,516	3,152
2008	52,703	27,892	5,194	2,595	6,153	1,399	1,451	518	4,478	3,023
2009	53,367	26,085	5,041	3,239	5,773	1,290	3,414	525	4,528	3,472
2010	57,615	29,098	4,824	3,316	6,430	1,123	3,409	481	5,720	3,214
<b>Aged 18-64</b>										
2006	474,074	272,946	105,254	4,612	13,542	27,701	4,762	3,368	29,007	12,882
2007	450,585	258,701	105,573	4,375	11,734	27,902	3,078	3,174	22,751	13,297
2008	460,763	262,551	107,354	4,482	12,499	27,382	4,611	3,153	26,184	12,547
2009	496,049	292,731	109,525	4,613	12,364	27,668	4,109	2,586	27,860	14,593
2010	552,787	351,258	109,559	4,884	15,398	25,472	5,615	2,050	28,942	9,609
<b>Aged 65 or older</b>										
2006	195,942	39,923	133,523	3,067	7,148	736	1,156	9,454	18	917
2007	184,772	34,061	131,314	2,630	5,850	744	778	8,588	17	790
2008	186,161	33,842	131,864	2,419	5,895	832	798	9,773	9	729
2009	183,068	35,954	128,114	2,361	6,010	838	676	8,229	20	866
2010	205,544	57,566	126,765	3,197	7,356	813	1,139	7,996	13	699

Source: Social Security Administration, *SSI Annual Statistical Report, 2010*.

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# Congress of the United States

## House of Representatives

### COMMITTEE ON WAYS AND MEANS

WASHINGTON, DC 20515

#### SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Mr. Jonathan Stein  
General Counsel  
Community Legal Services  
1424 Chestnut Street  
Philadelphia, Pennsylvania 19102-2505

Dear Mr. Stein:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated having the benefit of your experience as we seek to understand caseload trends and outcomes for recipients of program benefits.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business on Tuesday, November 15, 2011:

1. Your testimony points to medical research and "more specific, precise" diagnoses in an attempt to explain the rapidly rising number of reported cases of autism, ADHD and speech and language delay in children receiving SSI. You go on to note, "more precise diagnosis is generally viewed as an advance in childhood mental health treatment, as it facilitates better-tailored treatment for children with disabilities."

What evidence is there that children on SSI are receiving "better-tailored treatment" today? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such "better-tailored treatment"? Are children experiencing shorter durations of disability? Are more going to work as adults? Are there other data showing that children on SSI are receiving "better-tailored treatment," as your testimony suggests?

2. When you testified before this Subcommittee on February 2, 1995 on proposed changes to the SSI children's program, Subcommittee Chairman Clay Shaw of Florida asked you about one family that was collecting \$47,000 in SSI payments per year for two parents and seven children on SSI, or the equivalent of about \$70,000 today.

Here is how you responded to Chairman Shaw: "We have problems with that, and what we would say is – and we have a long list of reforms that we do not have time to get into, but we would say for very large families there should be some sort of family cap or graduated sliding scale of benefits."

The SSI program has not added a family cap or sliding scale of benefits since then, so each child remains eligible for almost \$700 per month in Federal SSI benefits alone today. Do you continue to support adding a family cap or sliding scale for benefits when multiple children are on SSI, as you did in 1995?

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Again, many thanks. Should we have further questions, we will be sure to contact you.

Sincerely,

A handwritten signature in black ink, appearing to read "Geoff Davis", with a stylized flourish extending from the end of the name.

Geoff Davis

**BEFORE THE U.S. HOUSE OF REPRESENTATIVES**

**COMMITTEE ON WAYS AND MEANS,**

**SUBCOMMITTEE ON HUMAN RESOURCES**

**WRITTEN RESPONSES TO SUPPLEMENTAL QUESTIONS FROM OCTOBER  
27, 2011, HEARING REGARDING SUPPLEMENTAL SECURITY INCOME  
(SSI) CHILDHOOD DISABILITY BENEFITS**

**JONATHAN M. STEIN**

**COMMUNITY LEGAL SERVICES, INC., PHILADELPHIA, PA**

**NOVEMBER 15, 2011**

Jonathan M. Stein, General Counsel

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1. Your testimony points to medical research and “more specific, precise” diagnoses in an attempt to explain the rapidly rising number of reported cases of autism, ADHD and speech and language delay in children receiving SSI. You go on to note, “more precise diagnosis is generally viewed as an advance in childhood mental health treatment, as it facilitates better-tailored treatment for children with disabilities.”

What evidence is there that children on SSI are receiving “better-tailored treatment” today? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such “better-tailored treatment”? Are children experiencing shorter durations of disability? Are more going to work as adults? Are there other data showing that children on SSI are receiving “better-tailored treatment,” as your testimony suggests?

Recent medical studies and reports overwhelmingly suggest significant advances in diagnosis and treatment of mental health disorders. Leading examples include “Evidence-Based Practice in Child and Adolescent Mental Health Services,” an oft-cited overview of recent advances in the field;<sup>1</sup> recent reports by the Institute of Medicine, such as Improving the Quality of Health Care for Mental and Substance-Use Conditions<sup>2</sup> and Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities;<sup>3</sup> and a 1999 report of the U.S. Surgeon General on mental health.<sup>4</sup>

To be clear, however, when I stated that there have been improvements in diagnosis and treatment of mental health disorders, I did not intend to suggest that children who apply for or receive SSI necessarily have access to or receive appropriate levels of what treatment options now exist. Nor did I mean to suggest that there exist such levels of treatment as to be able to “cure” children of all mental and behavioral impairments.

Mental illnesses are complex disorders that affect functioning at home, at school and in the community. Severe disorders typically affect children's behavioral, emotional, and cognitive and academic functioning. When left untreated or treated ineffectively, they can set off a cascade of problems that result in long-term consequences and costs to individuals, families, and society. Even when treatments (whether medication, psychosocial interventions or some combination thereof) are beneficial, it does not mean that all problems in functioning are resolved.

Moreover, as posited by several of the aforementioned leading medical studies and reports on this subject, while we may know *what* to do, that does not necessarily mean that we do it. This is particularly true for low-income children. It should come as no surprise that, as a general matter, children with health insurance get substantially better care—they enjoy better access to behavioral treatments, have better access to appropriate medications, and are more likely to receive care in a “medical home” setting.<sup>5</sup>

However, Medicaid coverage often falls short, especially for children with mental impairments. State Medicaid programs provide incredibly limited coverage of the most effective community-based mental health services for children. Restrictions as to frequency of covered visits and prescriptions can also pose a problem. For instance, a child may receive an initial assessment and diagnosis, but be limited thereafter to follow-

up therapy visits that are so few and far between as to render treatment ineffective. Likewise, Medicaid coverage rules can prevent a prescription from being refilled as needed in order to adjust and find the right dosage. For all children, whatever health insurance coverage they may have, the profoundly short supply of child mental health specialists (especially child psychiatrists) presents a serious barrier to effective treatment.

In sum, while improvements in diagnosis and treatment of mental health impairments are to be applauded, and mark significant progress on the road to "parity" (between physical and mental health), that alone is not enough. We must also ensure that children have access to effective treatments that will give them the best chance at managing their impairments. What's more, one must take into account the unfortunate fact that for many children, even when the most efficacious treatment is furnished, the improvement that results will be limited to symptom control and some functional improvement, but will not lead the child to no longer be disabled.

SSI is a critical lifeline for low-income families raising children with severe physical and mental impairments. While much is known about what works, in diagnosing and treating children with severe mental impairments, additional study continues to be needed. I would urge the Subcommittee to give serious consideration to commissioning a study by the Institute of Medicine that targets children receiving SSI, to add to what we know about this vulnerable population and how we could more effectively and more efficiently connect children on SSI with appropriate clinical services and treatments. The answer may be improved interagency collaboration and aligned service delivery; IOM would be well situated to study and render recommendations on this point.

2. When you testified before this Subcommittee on February 2, 1995 on proposed changes to the SSI children's program, Subcommittee Chairman Clay Shaw of Florida asked you about one family that was collecting \$47,000 in SSI payments per year for two parents and seven children on SSI, or the equivalent of about \$70,000 today.

Here is how you responded to Chairman Shaw: "We have problems with that, and what we would say is – and we have a long list of reforms that we do not have time to get into, but we would say for very large families there should be some sort of family cap or graduated sliding scale of benefits."

The SSI program has not added a family cap or sliding scale of benefits since then, so each child remains eligible for almost \$700 per month in Federal SSI benefits alone today. Do you continue to support adding a family cap or sliding scale for benefits when multiple children are on SSI, as you did in 1995?

Let me be clear: I do not support a family cap or sliding scale for SSI benefits. My testimony in 1995 referred to a hypothetical family, whose circumstances as described by Chairman Shaw would render it an extreme outlier.

It should be no surprise that some families contain more than one SSI recipient with a disability. Many physical and mental impairments are highly heritable, meaning that shared genetics and environment can increase the likelihood that more than one member of a family will have certain types of disabilities or health impairments.<sup>6</sup>

## Stein, Supplemental Questions on Children's SSI, Nov, 15, 2011

Reducing grant amounts paid to families with multiple children with disabilities would be nothing short of devastating to an already struggling group of families and children. Raising even one child with a disability is expensive. Medicaid and private insurance have limited or no coverage of many things that children with disabilities need—such as therapies to help children function in their families, communities and schools; adaptive equipment and devices to help with communication, mobility, eating and breathing; and other material supports.

These high costs lead many families caring for a disabled child to experience serious material hardships such as food insecurity, housing instability, and unmet medical needs. Research shows that families with children with disabilities are more likely to run out of food or skip meals, have their phone service shut off, postpone needed medical care, be unable to pay rent, and have to “double up” with others to prevent homelessness. Over 70% of low-income families that include children with disabilities report facing such material hardships.<sup>7</sup>

Furthermore, the earnings lost when a parent must stay home to care for a child with a severe disability can be significant. For low-income families with a disabled child, SSI can mean the difference between living above or below the poverty line;<sup>8</sup> being able to provide or going without basic necessities like food; and being able to keep a disabled child at home, or having to put the child in a costly institution to get the care he or she needs.

For families caring for *multiple* children with disabilities, the emotional and financial toll can be magnified considerably. Every child with disabilities has unique needs—such as therapies, medical care, adaptive equipment, medications, and other expenses that may not be covered by health insurance. These sorts of expenses are not shared across multiple children with disabilities. Low-income parents caring for children with disabilities are already hard-hit both financially and emotionally, trying to provide for their children's basic as well as special needs. Reducing the SSI amounts for families with multiple disabled children would only make it harder for these already hard-hit families to care for their children at home instead of in a costly institution. It would also push more already-vulnerable children below the poverty line.

###

As requested by Chairman Davis, I am also including written responses to supplement the oral responses that I was unable to complete during the October 27, 2011, hearing, due to insufficient time.

1. In response to the question posed to Mr. Wittenburg regarding employment and other outcomes of individuals with disabilities who received SSI as children, I stated that it comes as no surprise that individuals with disabilities have difficulty finding and maintaining employment, poor highschool graduation rates, and other disappointing “outcomes.” Mr. Wittenburg testified to poor outcomes of adults who received SSI as children. This statement is both incomplete and misleading,

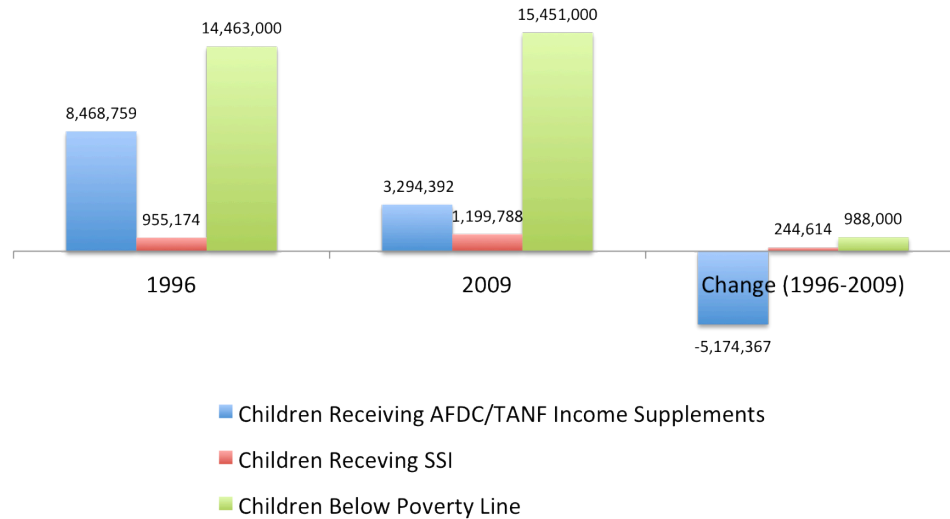
as the rates of employment and highschool graduation, etc., for adults with disabilities are low generally—whether or not they received SSI as children. Thus, one must compare the outcomes of individuals with disabilities who received SSI as children with the outcomes of individuals with disabilities generally, in order to isolate whether the receipt of SSI might play any role at all in driving outcomes, good or bad.

I hope we can all agree on the importance of providing support to individuals with disabilities—children as well as adults—to maximize their likelihood of attaining independence and self-support. There is no question that examining the available data on employment, academic and other outcomes for individuals with disabilities is of great value as we explore how best to support this population. However, we must be clear as we examine those data, not to draw unsupported conclusions. Many individuals with severe disabilities who received SSI as children may have rates of employment, academic success, and other outcome measures, below those of the general “non-disabled” population—but the data reflecting that trend must be compared against individuals with disabilities generally, before we can draw any conclusions about SSI’s role in shaping outcomes.

2. In response to the question posed to me by Ranking Member Doggett regarding what would happen if SSI were to be block-granted, I responded that block-granting SSI would be devastating to countless disabled children and their families. Instituting a block-grant funding structure would result in benefit cuts and children in need having to go without vital assistance. We have seen the result of converting Aid for Families with Dependent Children (AFDC) into Temporary Assistance for Needy Families (TANF), a block-grant funded program. In short, TANF has been largely unresponsive to our nation’s recent rise in poverty during the economic recession; indeed while the number of Americans in poverty climbed from 2006-2008, the TANF caseloads fell dramatically during that period. If SSI is converted to a block-grant program, many children with severe impairments will lose critically needed assistance.<sup>9</sup>

Testimony offered by Mr. Burkhauser and Mr. Wittenberg suggested that SSI provides states with a financial incentive to shift families from their state welfare assistance programs to SSI, and similarly, that it provides families with an incentive to seek SSI over “welfare” for their children because the SSI grant amount is higher. One critical piece of information is missing from this analysis: to qualify for SSI, it is not enough to be poor. One must also have a severe physical or mental impairment or combination of impairments that meets the stringent SSI disability standard. Thus, the alleged potential incentives assumed by Messrs. Burkhauser and Wittenburg (in their written as well and oral testimony) might well explain an increase in *applications* for SSI—but only children who meet the strict disability standard and financial eligibility criteria will receive benefits.

Indeed, despite concerns around the time of “welfare reform,” the increase in the number of children receiving SSI since 1996, when the reforms were implemented, is equal to just one-twentieth of the decline in the number of children receiving AFDC/TANF during that same period.



3. In response to the question posed to me by Ranking Member Doggett regarding “whether medications for disorders like ADHD reduce the likelihood of eligibility for SSI,” my time expired after I had the opportunity to say yes, that is correct. To complete my answer to this question, as Mr. Bertoni of the Government Accountability Office (GAO) stated in his “Preliminary Observations” report submitted as written testimony for this hearing, the fact that a child has been prescribed and is taking medications is “just one piece of the puzzle.”<sup>10</sup>

As any attorney who has represented children in SSI hearings can tell you, a prescription for medications of any kind is just one factor among many considered in determining eligibility, and would never on its own make a child eligible for SSI. Moreover, the SSI children’s disability determination process takes into account not just the *fact* of treatment but also the *effects* of treatment.<sup>11</sup> Thus, to the extent that any treatment (including psychotropic or other types of medications) improves a child’s functioning, the child is evaluated in terms of that improved functioning. Accordingly, putting a child on medication often *lessens* her chances of being found disabled and eligible for SSI.

Recent Social Security Administration data show that taking ADHD-related medications did not increase a child’s chances of being found eligible for SSI. An analysis of all applications of children with a primary diagnosis of ADHD in 2010,

showed that children with ADHD taking related medications were no more likely than those not taking medications to be found medically eligible for SSI. Indeed, the Boston Globe issued a correction on November 6, 2011, after the October 27, 2011, hearing on children's SSI, making clear that their original reporting on this topic was flawed.<sup>12</sup>

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<sup>1</sup> Hoagwood et al., Evidence-Based Practice in Child and Adolescent Mental Health Services, *Psychiatric Services*, Sep 2001; 52 (9): 1179-1189, available at <http://ps.psychiatryonline.org/article.aspx?articleid=86400>.

<sup>2</sup> Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders, Institute of Medicine, "Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series" (National Academies Press, 2006), available at <http://www.iom.edu/Reports/2005/Improving-the-Quality-of-Health-Care-for-Mental-and-Substance-Use-Conditions-Quality-Chasm-Series.aspx>.

<sup>3</sup> Committee on Prevention of Mental Disorders and Substance Abuse Among Children, Youth and Young Adults: Research Advances and Promising Interventions, Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education, National Research Council and Institute of Medicine, "Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities" (National Academies Press, 2009), available at <http://www.iom.edu/Reports/2009/Preventing-Mental-Emotional-and-Behavioral-Disorders-Among-Young-People-Progress-and-Possibilities.aspx>.

<sup>4</sup> Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General" (1999), available at <http://www.surgeongeneral.gov/library/mentalhealth/pdfs/front.pdf>.

<sup>5</sup> See, e.g., Kaiser Commission on Medicaid and the Uninsured, "The Impact of Medicaid and SCHIP on Low-Income Children's Health," Policy Brief No. 7645-02; see also, Finkelstein et al., "The Oregon Health Insurance Experiment: Evidence from the First Year," NBER Working Paper No. 17190 (July 2011), available at <http://www.nber.org/papers/w17190.pdf> (while this study involves adults, rather than children, the principles involved are the same and the study's results are interpreted by many to reflect the beneficial impact of health insurance through Medicaid on health outcomes, generally).

<sup>6</sup> See id.

<sup>7</sup> See, e.g., Susan Parish et al., "Material hardship in U.S. families raising children with disabilities," *Exceptional Children*, 75(1) (2008), at 71.

<sup>8</sup> Mark G. Duggan & Melissa Schettini Kearney, "The impact of child SSI enrollment on household outcomes," *Journal of Policy Analysis and Management*, 26(4)(2007), at 861.

<sup>9</sup> Schott, Liz, Center on Budget and Policy Priorities, "Policy Basics: An Introduction to TANF," (Rev. June 2011), available at <http://www.cbpp.org/cms/?fa=view&id=936>.

<sup>10</sup> Bertoni, Daniel, "Supplemental Security Income: Preliminary Observations on Children with Mental Impairments," Testimony Before the Subcommittee on Human Resources, Committee on Ways and Means, House of Representatives (October 27, 2011), at 16.

<sup>11</sup> 20 CFR §416.924a(b)(9).

## Stein, Supplemental Questions on Children's SSI, Nov, 15, 2011

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<sup>12</sup> Boston *Globe*, For the Record (Nov. 6, 2011), available at <http://www.bostonglobe.com/news/nation/2011/11/05/for-record/nrjLTFJoBuOZ5AL2EL62jK/story.html>.

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**Congress of the United States**  
**House of Representatives**  
**COMMITTEE ON WAYS AND MEANS**

WASHINGTON, DC 20515

SUBCOMMITTEE ON HUMAN RESOURCES

November 1, 2011

Elizabeth Roberts, M.D.  
25460 Medical Center Drive  
Suite 203  
Murrieta, California 92562

Dear Dr. Roberts:

Thank you for testifying at our subcommittee hearing on SSI benefits for children. We appreciated having the benefit of your expertise and on-the-ground experience.

In order to complete the record of the hearing, please respond to the following questions no later than the close of business on Tuesday, November 15, 2011:

1. In your experience, what features in a child's case help determine their eligibility for SSI? What is behind the behaviors that lead parents to promote a psychiatric illness such as ADHD to the evaluating doctor? What causes doctors to sometimes misdiagnose a child?
2. Are SSI payments a factor driving more diagnoses of ADHD and other mental and behavioral disorders in recent years? What should we as policymakers make of all this?
3. In Mr. Stein's testimony on October 27, 2011, he claimed that medical research and "more specific, and precise" diagnoses explain the rapidly rising number of reported cases of Autism, ADHD and speech and language delay among children receiving SSI. In your opinion what is causing this rapidly rising number of children being diagnosed with ADHD and other mental disorders such as Bipolar Disorder and Autism spectrum disorders both in the general public but especially among child SSI recipients?
4. What evidence have you seen that children on SSI are receiving "more specific, and precise" diagnoses and "better-tailored treatment" today, as Mr. Stein contended in his testimony? For example, are more children overcoming their disabilities and leaving the



SSI program as a result of such "better-tailored treatment"? If not, what do we need to do about that?

5. What in your view are the ramifications and consequences for the child whose parent seeks SSI simply because the family needs the extra income and not because the family needs special mental health treatment and educational services for their disabled child?
6. Would you care to comment on the long-term effects on a child's psyche and social functioning, when a child remains on the SSI rolls long after he or she has recovered from the disabling condition simply because a continuing disability review was not completed as required by law?
7. In your opinion, does the legitimate use of the SSI system by some children justify continuing to administer the current program without reforms? Do the benefits for some children justify the risks posed to others if children are wrongly diagnosed and categorized as disabled and possibly mis-prescribed powerful psychotropic medications?

The Committee relies on electronic submissions for printing of the official record. Therefore, please send an electronic submission in Word format to [timothy.ford@mail.house.gov](mailto:timothy.ford@mail.house.gov). If you have any questions concerning this matter, please feel free to contact Matt Weidinger or Anne DeCesaro of my staff at (202) 225-1025.

Again, many thanks for your excellent testimony. We will continue to be in touch as we have specific questions.

Sincerely,



Geoff Davis

Geoff Davis  
Kentucky Congressman  
Chairman of Subcommittee on Human Resources  
House of Representatives  
Committee on Ways and Means

November 7, 2011

Supplemental Security Income Benefits for Children  
Questions for Child Psychiatrist  
Elizabeth J. Roberts, M.D.

- 1. In your experience, what features in a child's case help determine their eligibility for SSI? What is behind the behaviors that lead parents to promote a psychiatric illness such as AD/HD to the evaluating doctor? What causes doctors to sometimes mis-diagnose a child?**

When a child applies for Supplemental Security Income (SSI) based on a mental illness, practice and policy are vastly different in determining eligibility. In spite of the policies outlined in the American Psychiatric Association's (APA) statement to this committee on October 27<sup>th</sup> 2011, in actual clinical practice, the one most salient feature, and typically the only factor that determines a child's eligibility for SSI benefits, is the doctor's report to the Social Security Administration (SSA). If the doctor's report to the SSA states that the child is functioning at a level significantly below the norm, then his benefits are generally granted. Doctors report to the SSA what the parents report to the doctor during the child's evaluation. Having no other data from which to make a determination about a child's condition, doctors must base their assessment to a large extent on what the parents report. A psychiatrist's encounter with a child during the assessment is usually very brief. When parents exaggerate their child's dysfunction during an SSI assessment, the evaluator can neither substantiate nor refute the claims of the parents. Thus the parent's report of the child's behavior is the primary clinical information that is passed along to the SSA. This is why diagnosing psychiatric illnesses in children is such a subjective process.

For many parents (not all parents) the motivation for seeking a diagnosis of AD/HD for their child is purely for the financial benefits of SSI. Parents have reported to me that SSI benefits are far easier to obtain than welfare benefits. Furthermore, with welfare benefits in most States there is a requirement that parents participate in a vocational training program. Parents have told me they prefer not to work and would rather just get the larger cash benefit provided by SSI, than to have to complete job training. Unfortunately, I have learned through my years of clinical practice, that there is a culture of entitlement in some families, as I am serving third generation SSI beneficiaries.

A doctor's mis-diagnosis of a child in psychiatry happens for a number of reasons. Parents and doctors don't communicate effectively. Doctors use terms that are misunderstood by parents. Parents omit details of their child's symptoms, such as trauma, family crises or drug abuse. In order to qualify for SSI, parents will exaggerated their child's symptoms to portray their child as more mentally ill than the child really is.

**2. Are SSI payments a factor in driving more diagnoses of AD/HD and other mental and behavioral disorders in recent years? What should we as policymakers make of all this?**

Absolutely, there is no doubt that there is a financial incentive which drives the incredible increase in applications for child SSI benefits based on a mental illness. Regardless of how many claims are denied, the fact remains, that the increase in applications is driven by the desire for money. It is well established amongst those seeking money through the SSI system that mental illness claims are the easiest to get. This perception is rooted in the fact that a psychiatric diagnosis in a child is based on set of behaviors that can be construed in a number of different ways. In other words, the defiant behavior of a belligerent child can easily be portrayed as AD/HD.

A good example of how the SSI payment drives more psychiatric diagnoses in children is the case of a 17 year old High School football player, I will call Joe. Joe's father brought him to me for the treatment of AD/HD. Joe had developed some symptoms of depression after he had broken his arm and was benched for the season. The father, an admitted drug-addict himself, sought amphetamine medications for his son's AD/HD. Although amphetamines are indeed a typical treatment for AD/HD, they are also a controlled and addicting substance. The father also wanted SSI benefits for his son, Joe. The father was very blunt stating that he knew that Joe was NOT disabled, and that his only reason for applying for SSI benefits was because, "The family could use the money." When the SSI benefits were denied, the family never returned for treatment of the Joe's depression or the AD/HD.

**3. In Mr. Stein's testimony on October 27, 2011, he claimed that medical research and "more specific, and precise" diagnoses explain the rapidly rising number of reported cases of Autism, AD/HD and speech and language delay in children receiving SSI. In your opinion, what is causing this rapidly rising number of children being diagnosed with AD/HD and other mental disorders such as Bipolar Disorder and Autism spectrum disorders both in the general public but especially among child SSI recipients?**

With all due respect to Mr. Stein, an attorney and an SSI advocate, he has only the statements made by administrators and board members of the APA from which to make his claims. Mr. Stein has not completed a degree in medicine, nor has he treated children with psychiatric illness, nor has he completed the evaluation of a child for their SSI benefits. I appreciate his desire to be helpful but he lacks personal experience or clinical insight to make the claims he has made. He is merely repeating what others have said.

For those of us who actually provide psychiatric care for poor families, we have a different explanation for why there has been a rapidly rising number of mental disorders diagnosed in children in the general public and among SSI applicants. The claim that medical research has led to more specific and precise diagnoses completely ignores the clinical realities of how and why children get a psychiatric diagnosis in the first place. I have no doubt that there have been improvements in the tools used to diagnose a child with a mental illness. The problem is that these tools are not often used by the psychiatrists who do most of the SSI evaluations.

The rise of mental disorders among children in the general public is a little more complicated. In a private practice, psychiatrists have to see a certain number of patients every hour to meet the costs of running their clinics and paying their employees. Reimbursement rates from insurance companies are too low to allow for the luxury of lengthy one to two hour evaluation with a child. So, these psychiatrists rush their patients in and out of their offices in 5 to 20 minutes with a diagnosis and a prescription in hand. This has been reported to me by both the families who endure this treatment and the psychiatrists who deliver this kind of service.

Parents play their part as well. Diagnosing a child with a psychiatric illness can meet a number of needs for a family regardless of socioeconomic group. First and foremost, there are, and always have been, a number of children who have legitimate, disabling mental illnesses for which psychiatric treatment is essential, such as Schizophrenia, Autism and many others. However, a psychiatric diagnosis can provide a parent with a rationale for their child's standard, typical poor behavior. The behavior of children who are rude to adults and socially awkward with peers can be explained away with a diagnosis of Asperger's. A defiant, belligerent child who refuses to comply with his teacher's directives can be excused with a diagnosis of AD/HD. And, if a moody, demanding child becomes particularly explosive and throws a tantrum when he doesn't get his way, then a diagnosis of Bipolar Disorder can justify this conduct. Blaming brain chemistry has become an acceptable way for parents to explain away their child's poor behaviors, without having to exam their own failing parenting style.

This in no way means to imply that there are not legitimate cases of psychiatric illnesses in children, of course there are. But, the astronomical rise in the number of psychiatric diagnoses in children in the general public, is better explained, at least to some degree, as the practice of diagnosing a child's every day bad behaviors as a psychiatric illness. On the other hand, for those in a lower socioeconomic group, the diagnosis of a child with a mental illness can be a gateway to financial aid. For these parents, their child's psychiatric diagnosis represents a financial benefit through the SSI program

The vast majority of parents research their child's behavior, before ever visiting a doctor for treatment. Parents search the Internet or ask friends, neighbors and teachers about their child's behaviors before seeking the advice of a doctor. These parents arrive at the doctor's office for their child's first assessment, having already made up their minds about their child's diagnosis. Doctors and therapists know that it is far easier to tell a parent that their child has a chemical imbalance than to tell the parent that they need to change their parenting methods. Accordingly, doctors find themselves agreeing with the diagnosis that the parent provides at the initial assessment rather than argue with the parent.

With or without a mental illness, many psychiatric medications, can improve a child's performance slightly. Though the improvement is minimal, this slight change validates the parent's claim that their child has a mental disorder and justifies the doctor's continued prescribing practice.

- 4. What evidence have you seen that children on SSI are receiving "more specific, and precise" diagnoses and "better-tailored treatment" today, as Mr. Stein contended in his testimony? For example, are more children overcoming their disabilities and leaving the SSI program as a result of such "better-tailored treatment"? If not, what do we need to do about that?**

Again, Mr. Stein is not a doctor nor he does not treat children. There is no evidence that he has even encountered the parents whose children have no true mental illness, but who are motivated purely by financial gain, in their pursuit of SSI. Mr. Stein may not be aware that many children, though poorly behaved, do NOT really have a true mental illness, but have nonetheless, been diagnosed with a psychiatric disorder. The child he brought into the hearing room on October 27<sup>th</sup> 2011 had a physical or neurological illness, a seizure disorder, not a psychiatric illness. My experience in psychiatry is that more often than not, as soon as the poor family receives their check from SSI, they return to our clinic only when absolutely necessary to maintain their benefits. The SSA does not check with the treating psychiatrist for regular updates about the child's compliance with medications or treatment. The families receiving SSI are aware of this lack of supervision by the SSA and know how to meet the minimal requirements to keep the checks coming.

SSI recipients don't receive any "better-tailored treatment" than any other child. In fact, these families often fail to comply with treatment altogether. There is no incentive for a family to end their SSI benefits and therefore no reason for a family to report any improvement in their child's condition. Even when a child does recover from his mental illness, there is no rush to see the doctor for a clean bill of health. These families realize that the child's recovery from the "disabling condition" means that they will lose their benefit check. In the case of Rebecca Riley, described in my written testimony, her parents continued to press Dr. Kifuji to complete the SSI application for Rebecca. In an effort to persuade the doctor that Rebecca was really ill, her parents exaggerated Rebecca's symptoms and kept pushing for ever stronger medication. Oddly, no one else in the family or at the school ever witnessed these symptoms. Rebecca's parents and her two siblings were already receiving four SSI checks amongst the four of them and all based on their psychiatric diagnoses. Tragically, the financial incentive for that fifth SSI check was so powerful that Rebecca's parents kept pushing her medication doses ever higher until they overdosed her and killed her. It is little wonder that the Boston Globe has taken such an interest in the misuse of the SSI program. A child had to die before anyone took notice of what some of us have been warning about for years.

There are many psychiatrists who feel pity for these poor families and will exaggerate the severity of the child's illness or leave out essential features of the child's condition (such as drug addiction) in order to slant the assessment in the favor getting SSI benefits for the family. In the case of Sarah, whom I described in my written testimony, her SSI benefits were reinstated a year later. Because her mother "needed the money to rebuild their burned down home," Sarah was reassigned to a different doctor at that same County clinic. This new psychiatrist was well known for the practice of skewing her reports to the SSA in order to get patients their SSI benefits. This doctor once completed a report for the SSA on a patient she had never met. This doctor merely interviewed the family member who wanted the patient to have a supplemental income source.

- 5. What in your view are the ramifications and consequences for the child whose parent seeks SSI simply because the family needs the extra income and not because the family needs special mental health treatment and educational services for their disabled child?**

In the treatment of children with a mental illness, there are no extra costs for “special mental health treatment.” These needs are already met through existing programs, such as Medicaid and public schools. Children with mental illnesses need visits with a doctor, medications and special education services. All the care that such a child would need is already provided, at no cost to a poor family, through Medicaid and public schools. But the SSI benefits program has become something else entirely. SSI benefits have become a substitute for a job for many poor parents and their only source of income. Some parents who have become very good at working the system, receive multiple checks for the psychiatric disorders of the various family members, as in the case of Rebecca Riley’s family.

When children are incorrectly diagnosed with a mental illness so that their parents can get an SSI check, these children are consequently and needlessly medicated. These medications often have serious, permanent and sometimes deadly side effects. Furthermore, when the SSI system is fraudulently used by some families, other children who really deserve the benefit such as, Will Bentley, may one day find that the funds are exhausted and the program is bankrupt.

**6. Would you care to comment on the long-term effects on the child’s psyche and social functioning, when a child remains on the SSI rolls long after he or she has recovered from the disabling condition simply because a continuing disability review was not completed as required by law?**

Children are extremely impressionable and their psyches are deeply impacted by their childhood experiences. If children are falsely led to believe that they are disabled, then they give up on themselves. They come to believe that they are less of a person, unworthy of or incapable of achieving what normal children can. This, in effect, diminishes the child. As adults they carry the self-image of one who cannot provide for himself because he is “disabled.” He then becomes a permanent member of the dependent class of citizens who feel entitled to be provided for by government programs their entire lives. When families are acquiring their SSI fraudulently, the child can come to view defrauding the government as justifiable and a clever scam, as Sarah had. The misuse of the SSI system can corrupt a child’s incentive to be productive, self-sufficient, independent, self-respecting and law abiding. Disability reviews done at the intervals currently dictated by law are already too infrequent to catch all those who have successfully recovered from their psychiatric illness. Clearly, missing the regular reviews that are required by law, simply exacerbates the problem.

**7. In your opinion, does the legitimate use of the SSI system by some children, justify continuing to administer the current program without reforms? Do the benefits for some children, justify the risks posed to other children who have been wrongly diagnosed and categorized as disabled and possibly mis-prescribed powerful psychotropic medications?**

Clearly, this question answers itself. How can policy makers stand by and watch the destruction of children’s lives when they have the power to reform an entitlement program that is hurting so many children. The fact that the Will Bentley’s of the world would be inconvenienced by being required to endure a review every year by an independent physician in order to save the lives of the Sarah’s and the Rebecca’s, seems a small price to pay. Furthermore, the current practice of awarding lawyers a regular portion of a family’s SSI check when the attorney sues in court for a

child's SSI benefits, just adds another layer of potential misconduct and abuse of a system already fraught with fraud.

To turn a blind eye to the devastating, and at times deadly unintended consequences of this government behemoth, SSI, is to turn one's back on some children not deemed worthy enough of our concern. I know that your committee, Mr. Chairman, is full of honorable men and women who want to do what is right for children everywhere. Therefore, I implore you to look carefully at what good intentions have wrought.